



King's Research Portal

DOI:

[10.1080/14659891.2016.1259367](https://doi.org/10.1080/14659891.2016.1259367)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Neale, J., Black, L., Getty, M., Hogan, C., Lennon, P., Lora, C., McDonald, R., Strang, J., Tompkins, C., Usher, J., Villa, G., & Wylie, A. (2017). Paying participants in addiction research: is cash king? *Journal of Substance Use*, 22(5), 1-3. <https://doi.org/10.1080/14659891.2016.1259367>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

PAYING PARTICIPANTS IN ADDICTION RESEARCH – IS CASH KING?

Joanne Neale, Reader^{1, 2}
Lavinia Black, SURG member²
Mel Getty, SURG member²
Cassandra Hogan, SURG member²
Paul Lennon, SURG member²
Cristina Lora, SURG member²
Rebecca McDonald, PhD student¹
John Strang, Professor¹
Charlotte Tompkins, Post Doctoral Research Worker¹
John Usher, SURG member²
Gina Villa, SURG member²
Alan Wylie, SURG member²
(on behalf the IoPPN and Aurora SURG)

¹ National Addiction Centre, King's College London, 4 Windsor Walk,
Denmark Hill, London, SE5 8BB

² Service User Research Group (SURG), c/o Aurora Project, 140 Stockwell
Road, Brixton, London, SW9 9TQ

Corresponding Author

Joanne Neale
Reader in Qualitative and Mixed Methods Research
National Addiction Centre
King's College London
4 Windsor Walk
Denmark Hill
London
SE5 8BB
Email: joanne.neale@kcl.ac.uk

Shortened title: PAYING PARTICIPANTS IN ADDICTION RESEARCH

TITLE: PAYING PARTICIPANTS IN ADDICTION RESEARCH – IS CASH KING?

MANUSCRIPT TYPE:

OPINION PIECE (NOT PEER REVIEWED)

KEY WORDS:

RESEARCH, ADDICTION, PAYMENTS, CASH, VOUCHERS

DECLARATION OF INTERESTS:

Joanne Neale is part-funded by, and John Strang is supported by, the National Institute for Health Research (NIHR) Biomedical Research Centre for Mental Health at South London and Maudsley NHS Foundation Trust and King's College London. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health. JN receives honoraria and some expenses from *Addiction* journal in her role as Commissioning Editor and Senior Qualitative Editor. JS is a researcher and clinician who has worked with a range of types of treatment and rehabilitation service-providers. He has also worked with a range of governmental and non-governmental organisations, and with pharmaceutical companies to seek to identify new or improved treatments from whom he and his employer (King's College London) have received honoraria, travel costs and/or consultancy payments. This includes work with (past 3 years) Martindale, Reckitt-Benckiser/Indivior, MundiPharma, Braeburn/MedPace and trial medication supply from iGen. His employer (King's College London) has registered intellectual property on a novel buccal naloxone formulation and he has also been named in a patent registration by a Pharma company as inventor of a concentrated nasal naloxone spray. For a fuller account, see JS's web-page at <http://www.kcl.ac.uk/ioppn/depts/addictions/people/hod.aspx>. JS and JN have additionally received project grant support from Mundipharma for exploration of patient perspectives on medication formulation options and also perspectives on clinical trial participation; this research, involving CT and RM, is in preparation.

PAYING PARTICIPANTS IN ADDICTION RESEARCH – IS CASH KING?

“I know there’s some real scary, hardcore stories of people selling vouchers, but I’ve never experienced anything like that. If I got a voucher, I would often see it as a bonus. If it was for a shop I didn’t use, I would sell it to someone I knew for the same amount of money - them just doing me a favour really. I wouldn’t sell a voucher for less than its value.”

The National Addiction Centre (NAC) at King’s College London (UK) and the Aurora Project in Lambeth (UK) jointly organise an addiction Service User Research Group (SURG)¹. The SURG operates as a Patient and Public Involvement (PPI) panel for addiction researchers; that is, its central aim is to build meaningful and reciprocal relationships between addiction researchers and addiction service users when thinking through research problems, designing studies, preparing grant applications and ultimately conducting studies. Researchers from the NAC book initial advice sessions with the SURG to talk about their research and to establish relationships with group members who can then go on to be co-applicants or collaborators on studies.

In one recent advice session, SURG members began an impromptu discussion about whether participants in addiction research studies should be ‘paid’² in cash or by voucher. There is a small and useful literature on paying participants in addiction research (e.g. Fry et al., 2005, 2006; Ritter et al., 2003; Seddon, 2005), but these publications largely focus on ethical and to a lesser extent practical concerns from a researcher perspective. In contrast, very little seems to be known about how research participants themselves view payments (for a useful exception see Slomka et al., 2007). Obviously, the SURG is just one group, in one city, so we do not propose to offer any definitive statements or conclusions on this topic. However, our discussion (which continued later by email) highlighted a number of issues that seem likely to be of interest to other researchers, ethics committee members, and (of course) study participants.

¹ The SURG is financially supported by the National Institute for Health Research (NIHR) Biomedical Research Centre for Mental Health at South London and Maudsley NHS Foundation Trust and King's College London.

² We use the term ‘paying’ here, but recognise that other terms (e.g. ‘compensating’, ‘incentivising’, ‘reimbursing’, ‘rewarding’) might be equally valid.

To begin, SURG members identified various benefits of cash payments. On a practical level, cash was considered simple, easy, and convenient: “you can spend it on what you want, when you want, and where you want”. In addition, cash has important symbolic value, signifying “a genuine appreciation of the participant’s time and contribution”. Further, giving a research participant cash indicates “respect” and “trust” in the participant; so “treating them like an adult”. As such, cash was perceived as “empowering”, “non-stigmatizing” and “potentially encouraging of recovery”; cash was “king”. Despite this, group members also acknowledged that cash could easily be spent on drugs or alcohol and this might be the main factor motivating individuals to participate in a study. Even so, there was agreement that in practice the amounts of money offered by studies were nearly always too small to raise any significant safety or ethical concerns, even when study payments were used to buy substances.

Overall, SURG members reported fewer benefits of vouchers compared with cash. Some suggested that vouchers might be better for people who were still using substances as vouchers may remove the “temptation to spend money unwisely”. Moreover, vouchers could “encourage people to spend on things that they need” (e.g. food). If people chose to sell vouchers for cash, then group members generally did not feel that that was the responsibility of researchers. In contrast, vouchers seemed to have many disadvantages. For example, vouchers have to be spent in certain shops and/ or on certain things. They also expire and part of the value is lost if goods purchased do not match the value of the voucher (since most retailers do not give cash change). Equally importantly, vouchers can convey lack of trust and “an assumption” that cash would be spent on drugs or alcohol. Indeed, some group members felt very strongly that vouchers were “degrading”, “patronizing” or “insulting”:

“I’m mindful of all the issues involved, and the policies already in place, but it’s a matter of respect... I know that some people might be vulnerable to temptation, but, then, when do we qualify for being acknowledged as independent thinkers, and able enough to make own choices?”

More unexpectedly, at least for the researchers present, vouchers were described as “dangerous”. SURG members believed that study participants who desperately needed drugs or alcohol might feel they “have to sell their vouchers” and reselling involved finding a “dodgy street dealer” who would accept vouchers, then further bargaining over the value of

the vouchers (in terms of either cash or drugs). This led to additional discussions about the resale value of a study voucher, with general agreement being that locally vouchers were exchangeable for half their cash value (i.e. a £20 voucher = £10 cash). In this regard, vouchers were described as “obstacles”. That is, a voucher would not prevent a research payment from being spent on drugs or alcohol; it simply made the process longer, trickier and, in consequence, “riskier”.

From here, the discussion turned to the type of voucher being offered. All group members agreed that vouchers should be easy to redeem – so multi outlet (high street) vouchers that could be redeemed in a number of stores were preferred over single outlet vouchers. In addition, vouchers for cheaper supermarkets were generally preferred over vouchers for more expensive supermarkets - as more goods could be bought (although with the caveat that the resale value of a more upmarket supermarket voucher was estimated to be greater than the equivalent voucher for a budget store). In terms of the amount of payment, £7.50 or less was regarded as insulting. Meanwhile, some group members felt that payment should be capped at £20 per half day’s time, some felt that no sum could be too much, and others felt that the amount should depend on what the participant was being asked to do and for how long. As a couple of group members noted, the London living wage is £9:40 per hour and it might be best to ask the question the other way around: “what would researchers expect to be paid for an hour’s work?”.

The importance of researchers talking to study participants about what was being paid and why was also emphasised. For example, some group members remembered how they been happy to accept vouchers after researchers had explained to them at the very outset that it was hospital or university policy only to offer vouchers (even though they felt that such policies should be challenged as they were discriminatory). Some group members stated that they were also willing to accept vouchers when involved in studies where some participants were vulnerable and might use cash payments “unwisely”. Interestingly, group members were also very mindful of the effects that offering payment by cash or voucher might have on study recruitment and sample bias. Specifically, cash was considered to be better at attracting a wider range of participants, including those with ongoing substance use issues. In contrast, vouchers were perceived as biasing recruitment towards participants who are more “stable” in treatment: “I just know that I would have done cash studies when I was active [drinking] and wouldn't have done voucher studies”.

So is cash always king? Some group members thought so, but some were less sure: “an easily redeemed voucher would also be good in my mind”. Others agreed that it very much depended on someone’s stage in recovery, with people who were “later on in recovery” becoming more “tolerant” and “accepting” of vouchers. As one group member explained:

“When I think back... my preference would have been cash, because it was easier to buy cigarettes and things like that... Fast forward a few years and my opinion has changed. Now I’ve got more control of my finances, I don’t mind vouchers as I can use them to buy my nieces and nephews presents. Or I can save them for a rainy day if I need to replace something at home. So for me, it has depended on what state my finances and life were in.”

As we see, even amongst one small group of service users we find very different views, as well as recognition that views change over time and depending on myriad factors, such as the amount of the payment, the ease of redeeming a voucher, what the research involved, the explanation of the payment method offered by the researchers, personal stage of recovery, and a participant’s personal finances. If we want an academic term to capture this, we might argue that payment for participation in research constitutes an ‘assemblage’ (Deleuze and Guattari, 1980). By this we mean, it is not fixed or stable, but relates to complex constellations of material and non-material factors and the relationships between those factors. We cannot understand payments without connecting them to the social contexts in which they are made and received, the actors involved, and the power dynamics and politics at play.

It is clear that our group has no concrete answers; we have simply scratched the surface of a complex issue needing further study. However, the discussion has at least two implications. First, researchers and ethics committee members should not be prescriptive about how to pay participants in addiction research; there is no simple simple answer. Second, in planning their studies, researchers need to consult with members of their target participant population to ensure that the decisions they make about payment are well informed. (c.f. Fry et al., 2006). Payment for participation in research is variously ‘compensation’, ‘incentive’, ‘reimbursement’, ‘reward’, ‘insult’, ‘danger’, ‘obstacle’, ‘recruitment method’, and ‘king’. Researchers should remember this. Meanwhile, the reflections reported here have potential

relevance beyond the world of research. Those working in the addiction field are increasingly delivering interventions (e.g. personal budgets and contingency management) that also involve offering people who use drugs or alcohol money, vouchers or material goods that have an exchangeable cash value. The meanings attributed to such ‘payments’ similarly need to be considered very carefully from the recipients’ perspectives, particularly if we want to avoid negative unintended consequences.

REFERENCES

- Deleuze, G. and Guattari, F. (1980) *A Thousand Plateaus. Capitalism and Schizophrenia*. London and New York: Continuum.
- Fry, C.L., Ritter, A. Baldwin, S., Bowen, K., Gardiner, P., Holt, T., Jenkinson, R.A. and Johnston, J. (2005) Paying research subjects: a study of current practices in Australia. *Journal of Medical Ethics*, 31, 542-547.
- Fry, C.L., Hall, W., Ritter, A. and Jenkinson, R. (2006) The ethics of paying drug users who participate in research: a review and practical recommendations. *Journal of Empirical Research on Human Research ethics*, 1, 21-36.
- Ritter, A., Fry, C.L. and Swan, A. (2003) The ethics of reimbursing drug users for public health research interviews: what price are we prepared to pay? *International Journal of Drug Policy*, 14, 1-3.
- Seddon, T. (2005) Paying drug users to take part in research: justice, human rights and business perspectives on the use of incentive payments. *Addiction Research and Theory*, 13, 101-109.
- Slomka, J., McCurdy, S., Ratliff, E.A., Timpson, S. and Williams, M.L. (2007) Perceptions of financial payment for research participation among African-American drug users in HIV studies. *Journal of General Internal Medicine*, 10, 1403-1409.